Gene Editing:

A survey of public opinion

Bristows

Introduction: Executive summary

Since the CRISPR breakthrough in 2012, genome editing has been the focus of a huge amount of attention and debate, thanks in part to its incredible potential: delivering personalised gene-medicines, and preventing the inheritance of genetic conditions.

Human genome editing is prohibited virtually everywhere. However, such is its promise that the international scientific and medical establishments have begun to turn their minds to the clinical standards and governance frameworks that would be needed if it were to become lawful. Whether it ever does will depend on how the public responds to truly epic questions of bioethics.

- Should we allow the implantation of edited embryos to prevent them suffering serious genetic disease once born?
- Should we allow it for the purpose of benefitting future generations?
- Why not for the purpose of "enhancing" human characteristics?
- Could genome editing deepen social divisions?
- What are the dangers of commercial monopolisation?
- How can we avoid potential harms?
- What, in fact, does society in general think about all of this?

With regard to the last question, in May 2016, researchers from Australian universities published the results of a global survey on attitudes towards gene editing. Their report is available online[i], and shows popular support, with around 60% of respondents "agreeing" to the use of gene editing to cure life threatening and debilitating diseases including via germline editing (editing the embryo). However, support for its use for non-health related purposes, like selecting eye colour or intelligence, drop substantially (around 30%).

Three years and several CRISPR-driven gene editing developments later, we decided to see if public opinion on the topic has changed, and if so, how.

One event seemed likely to have provoked public reflection. In November 2018, the Chinese physicist He Jiankui announced that he had successfully edited human embryos to disable a specific gene, attempting to make them immune to HIV, and that two such embryos were now healthy baby girls. His announcement was widely reported on by global media[ii], and lambasted by many in the scientific community who condemned embryonic editing or considered his methodology to be unethical, who supported an international moratorium. The incident also excited more general debate over human germline editing. Does the general population agree with the scientists?

To check whether the debate has reached the wider audience, and with the permission of its authors, we have endeavoured to replicate their research in the United Kingdom, using a nationally representative sample of the general population. We used Censuswide to run the survey[2].

The Results

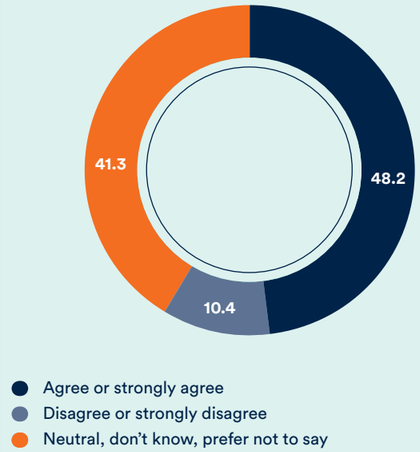
What we found is that public opinion is still split: nearly half of the respondents agree with the use of genetic editing to cure debilitating and life-threatening diseases, around a fifth are neutral and around a tenth disagree.

The numbers don't change much when respondents were asked about gene editing in embryos. We could interpret this to mean that when it comes to diseases that seriously affect or threaten lives, people don't feel strongly if the gene editing procedure is done on one individual only or on the germline. Instead, they appear to focus on the technique itself and on the reasons for using it.

In contrast, the general opinion is turned the opposite way when it comes to using gene editing to change non-disease characteristics. Only one in five respondents agreed with genome editing to alter physical appearance, intelligence or sporting ability, and almost half of the respondents are against it.

If popular opinion is consistent across the world, as the 2016 research found, this would mean that regulators could, in principle, draw a clear line demarcating what is allowed in human genome editing and what must ethically remain off limits. Respondents to our survey widely rejected eugenics, while allowing genome and germline editing for the purpose of saving and improving the lives of people with genetic conditions.

To what extent do you agree or disagree with the use of genetic editing of cells in children or adults to cure a life threatening disease? (%)



Interestingly, this trend was consistent no matter if respondents identified themselves as religious or non-religious. Perhaps unsurprisingly, higher levels of education tend to correlate with people being more agreeable about the use of clinical gene editing techniques. This is also in line with the findings from the 2016 research.

We hope that this report will serve as a prompt for all the actors involved: scientists developing new gene editing techniques, associations and companies in the sector, governments and intergovernmental entities regulating this field, patients who look to the clinical promise of genome editing, and the media writing about the topic – to keep talking openly and objectively about genome editing and its powerful potential, in order to fuel a healthy debate.

1 See the notes at the end of the whitepaper for more details on methodology and sample.

Our findings

Nearly half (46-48%) of respondents agree with the use of gene editing in children/adults to cure a life-threatening or debilitating disease.

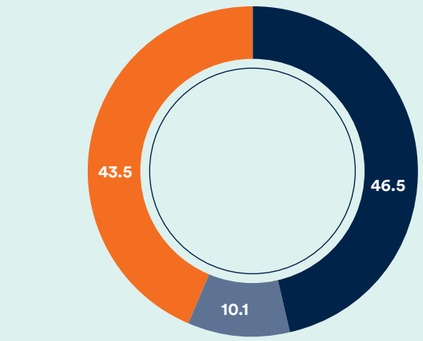
When it comes to using genetic engineering to cure a life-threatening disease, nearly half (48%) of those polled agreed that it was okay to do this in children and adults, even though it means the disease could still be passed on to their children. 19% of this total expressed strong agreement. Only 1 in 10 (10%) outwardly disagreed with the use of genetic editing in this circumstance.

A similar number (46%) of those also agree with the use of editing cells in children and adults to cure a debilitating disease. 17% of the sample "strongly agreed" with this prospect. Again, 10% of respondents disagreed with this specific use of genetic editing.

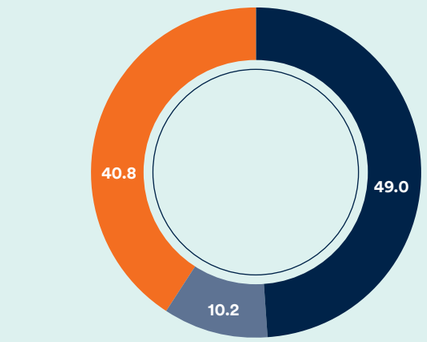
It appears that there is a consistent trend between opinions on genetic editing for life-threatening and debilitating diseases in adults and children.

We then posed the same questions to respondents, but this time asking if they would agree on the use of germline editing techniques, which is done at a much earlier stage of human development – editing the cells of embryos, gametes or precursor cells.

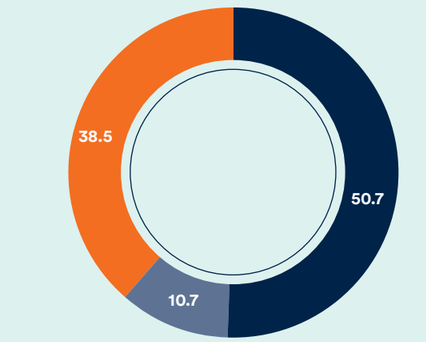
To what extent do you agree or disagree with the use of genetic editing of cells in children or adults to cure a debilitating disease? This means the disease could still be passed on to their children (%)



To what extent do you agree or disagree with the use of genetic editing of cells in embryos to cure a life threatening disease? (%)



To what extent do you agree or disagree with the use of genetic editing of cells in embryos to cure a debilitating disease? (%)



The shift to earlier genetic editing didn't sway the opinions of respondents drastically, seeing a 1% increase in genetic editing for a life-threatening disease (49%) and a 5% increase for a debilitating disease (51%).

The research suggests that overall levels of agreement and disagreement stay at similar levels despite the use of engineering at embryonic or child/adult stages and that a proportion of people are happy to use science to eradicate life-threatening and debilitating disease. It could be that responses to this situation are based on quality of life and being free of disease, compared to the act of tampering with genetic makeup.

Our findings continued

Few respondents are happy about the use of genetic engineering in embryos to modify non-disease traits and characteristics.

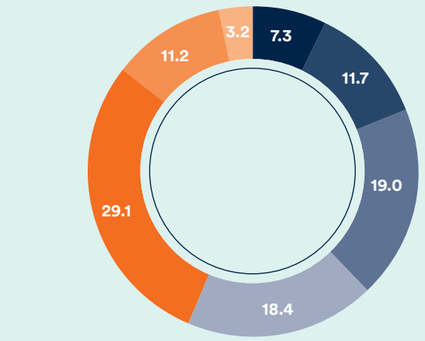
When asked about using germline editing to alter non-disease related characteristics the number of people who agreed with this is halved. Just under 1 in 5 (19%) agreed with the use of genetic editing to alter memory, eye colour, height or similar traits.

This indicates that almost half (47.5%) of people would not be happy for all future generations to have the same selected genetic characteristics.

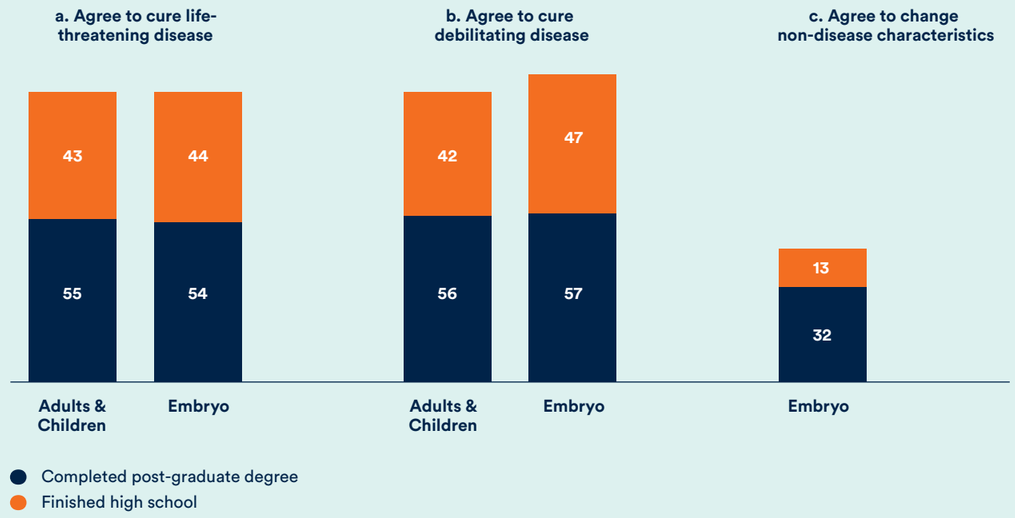
The same respondents answered a few more questions to see how far they would be happy to genetically edit their embryo, if it could be done safely. The majority (60%) said they would be happy to determine physical appearance (such as eye colour, hair colour, and skin colour). Similar numbers (61%) would also use this technology to determine their child's intelligence, and strength or sporting ability (59%).

It looks like the general attitude is still negative towards those Gattaca-like scenarios, very dear to science fiction authors, where eugenics is allowed and actively practiced, in which future children are selected by their characteristics; their status in life technologically determined before they are even conceived.

To what extent do you agree or disagree with the use of genetic editing of cells in embryos to alter any non-disease characteristic such as memory, eye colour or height? (%)



Comparisons on Level of Education (Q1-Q5) – Genetic editing on adults + children (%)



Respondents who finished their postgraduate degree consistently show higher levels of agreement than those who completed high school.

While we didn't go as far as to run a multiple logistic regression analysis to the data, as in the 2016 research, we still segmented the data on several variables, one of which is the level of education of the respondents.

Across the situational questions, those who completed their postgraduate degree consistently showed the overall highest level of agreeableness to the use of genetic editing techniques compared to those who only completed high school.

The results show that there is a minimum range of 10% between these two levels of education with the highest range existing in the opinions of the use of editing cells for non-disease characteristics (19% agreement generally).

Our findings continued

Respondents with religious beliefs have similar viewpoints to non-religious respondents on the use of genetic engineering in both children/adults and embryos.

Another segment that may have some impact on an individual's view on genetically engineering aspects of a person's biology is their religious beliefs. The 2016 research showed that:

"Respondents who reported a religious affiliation, particularly Christians, were notably more likely than those who did not to reject any application of genetic editing..."

... but we didn't notice such a difference.

When looking at life-threatening illnesses, nearly half (49%) of those who classify themselves as religious agree with the use of genetic engineering of cells in children or adults to cure it, compared to less than half (47%) of those who classify themselves as non-religious.

The difference of agreeableness remains at a similar level when respondents were asked to consider using genetic editing to cure a debilitating disease (Religious – 47% agree, Non-religious 46% agree). When looking at those who disagree there is a 1% difference between religious (11%) vs non-religious (10%) people. The results suggest that religious beliefs do not dictate opinions on genetic editing as much as education.

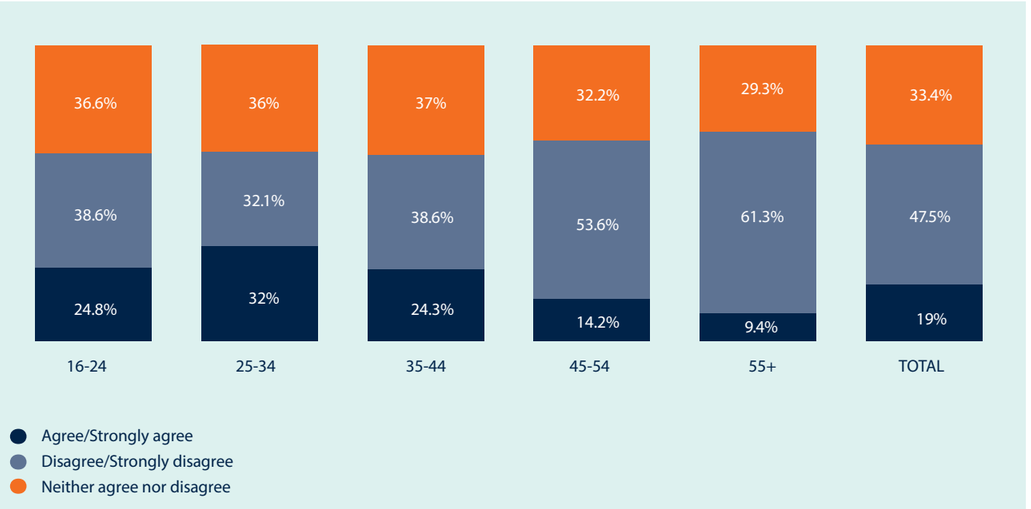
Despite the traditional resistance of some religious groups to embryonic stem cell research, embryo manipulation and some levels of reproductive medicine, we didn't see a massive difference in the responses of religious respondents when we asked about their opinion on germline editing to cure diseases. The results indicated a 2% difference in opinions of religious and non-religious individuals (49% of religious people agree compared to 51% of non-religious people agree).

The results indicate that on the whole religious and non-religious respondents have similar levels of tolerance to human genome editing. This suggests that an individual's religion does not make their views on the subject any stronger or weaker.

Older respondents were consistently more opposed to the use of gene editing techniques in embryos to alter non disease characteristics.

We didn't find that respondents from different age groups answered consistently in different ways, with the level of agreeableness to the use of gene editing in disease-curing scenarios being very similar.

However, when asked if they would agree with the use of genome editing in embryos to alter non-disease characteristics, the majority of respondents in the 55+ group were opposed (61%), way more than in respondents under 44 years of age (39%, 32%, 39% disagreed).



Last word

The results of this survey suggest that when it comes to human genome editing there are certain circumstances in which gene editing is not considered ethical: when the goal is to select characteristics that are somehow viewed as "enhancements".

From the data collected, when gene editing's purpose is not to cure a disease, fewer people are likely to agree with its use.

In terms of bettering disease-based traits, the level of agreement is around 50%, with a significant proportion of respondents who are neutral (around 20%) or don't know (around 10%). Around 10% of the respondents were definitely against gene editing, no matter if used on embryos or not.

This suggests that opinions on human genome editing are still divided in the UK.

An individual's level of education is likely to produce stronger opinions compared to if someone is religious or not, while age has an influence only in scenarios where gene editing is used for non-medical purposes.

Bristows urges increased attention to the appropriate regulation and governance of this significant field. It will be interesting to see whether legislators worldwide can agree on what to allow and what to forbid, and if –and at what level- the different groups and populations around the world will be involved in the decisions.

We think that the scientific community should encourage a healthy debate, that governments should make sure that people are well informed by offering a variety of sources providing clear explanation of the scientific and ethical implications of genetic engineering, that media and lobbying groups should avoid, prevent and counter scaremongering as much as they can, with a flow of objective information.

On our side, we hope we are providing at least a small contribution to the debate, with this survey, articles we've written on the topic, and our other activities, which for 2019 culminated with the organisation of a gene editing debate, held at The Royal Society in London, 12 November and entitled "The quest for the perfect human…?"

Besides our four expert panellists, we have invited regulators, researchers, ethicists, patient groups, journalists and other professionals in the pharmaceutical and technology sectors. We'll make the summary and recording of the Bristows debate public with the hope that, paired with the data shown in this report, it will help anyone who wants to know more about human genome editing to form an opinion.

About Bristows

We are the world's specialist law firm for clients that innovate. We help clients grow in life sciences, technology and other dynamic sectors. Clients on the edge of tomorrow; those creating new technologies and ideas, and those embracing them.

We have one of the most highly-regarded life sciences practices in the world. We pride ourselves on the breadth of our client base in the sector and actively seek to advise clients from the different key participants making up the life sciences eco-system.

We have a true cross-disciplinary team of over 80 lawyers in this space encompassing our renowned IP practice, regulatory, competition, transactional, dispute resolution, IT and data protection teams. The strength of each individual practice complements the others to provide a fully integrated and comprehensive service.

Our life sciences specialists – many with backgrounds in biology, chemistry, biochemistry, genetics and neuroscience – work with leading clients across the private, public and academic sectors. As such we act for global pharma, specialist investors, growing biotech and medtech companies, universities and research institutes, specialist service providers and government funded bodies. Our clients also include tech companies now entering the sector as convergence takes hold.

We believe that these different perspectives help us to best advise our clients and give us deep expertise in relation to the sectors we act for and where they are heading.

We often organise debates, roundtables and seminars with academics, professionals, experts to discuss innovations in many fields, and we commission public surveys (such as this one) to promote discussion on the most controversial of them. Besides human genome editing Bristows has – just in the last two years - held events on robotics and artificial intelligence, data protection, diversity in the City, the fintech sector, the new Medical Devices Regulations, adtech, competition law development, tax technology, automated vehicles, litigation in the biosimilar sector, and more.

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Notes

This research was conducted by Censuswide, with a sample of 2,004 nationally representative general consumers in the UK, between 11th and 15th October 2019. It comprised 8 substantive multiple choice questions, in addition to questions to capture respondents' demographic details. We used a five-point Likert scale to gauge agreeableness to specific use of genome editing techniques.

For this analysis, comments have only been made on demographic splits with more than 50 respondents. Any demographic split with less than 50 respondents have been disregarded as the margin of error increases and reliability of these results is less.

Full data available online on request – please email Valentina.Ciolino@Bristows.com

i https://www.sciencedirect.com/science/article/pii/S1934590916300546#app2 Tristan McCaughey, Paul G. Sanfilippo, George E.C. Gooden, David M. Budden, Li Fan, Eva Fenwick, Gwyneth Rees, Casimir MacGregor, Lei Si, Christine Chen, Helena Hai Liang, Timothy Baldwin, Alice Pe´bay,and Alex W. Hewitt, study supported by Australian National Health and Medical Research Council Fellowships (P.G.S. and A.W.H.), Australian Research Council Future Fellowships (T.B. and A.P.), the BrightFocus Foundation, Retina Australia, the Ophthalmic Research Institute of Australia, and Operational Infrastructure Support from the Victorian Government.

ii Some examples include BBC News: https://www.bbc.co.uk/news/world-asia-china-46382662, CNN: https://edition.cnn.com/2018/11/29/health/human-genome-summit-investigation-intl/index.html, Wall Street Journal https://www.wsj.com/articles/gene-edited-babies-experiment-raises-concerns-11544616000, Le Monde: https://www.lemonde.fr/sciences/article/2018/11/28/scandale-des-bebes-ogm-le-chercheur-chinois-responsable-fait-une-pause-dans-ses-recherches_5389666_1650684.html, El Pais: https://elpais.com/elpais/2018/11/28/ciencia/1543426962_870111.html, and Bild: https://www.bild.de/news/ausland/news-ausland/gentechnologie-forscher-designer-babys-in-china-geboren-58647586.bild.html

iii See https://www.cell.com/cell-stem-cell/fulltext/S1934-5909(16)30054-6, Figure 2, Table S1.

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